

General

Title

Caregiver satisfaction during the bereavement phase of end-of-life care: mean scale score on the "Illness Management" domain on the CANHELP Bereavement Questionnaire.

Source(s)

Heyland DK. Canadian Health Care Evaluation Project (CANHELP) bereavement questionnaire. Ontario (Canada): Canadian Researchers at the End of Life Network (CARENET); 2014 Nov 11. 9 p.

Measure Domain

Primary Measure Domain

Clinical Quality Measures: Patient Experience

Secondary Measure Domain

Does not apply to this measure

Brief Abstract

Description

This measure is used to assess the mean scale score on the "Illness Management" domain on the Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire.

A mean scale score is calculated based on the caregivers' ratings (1 = "Not at All Satisfied"; 2 = "Not Very Satisfied"; 3 = "Somewhat Satisfied"; 4 = "Very Satisfied"; 5 = "Completely Satisfied") on the following questions:

How satisfied are you with the tests that were done and the treatments that were given for your relative's medical problems *in the last month of life*?

How satisfied are you that physical symptoms (for example: pain, shortness of breath, nausea) your relative had *in the last month of life* were adequately assessed and controlled?

How satisfied are you that emotional problems (for example: depression, anxiety) your relative had *in the last month of life* were adequately controlled?

How satisfied are you with the help your relative received with personal care *in the last month of life* (for example: bathing, toileting, dressing, eating)?

How satisfied are you that, *in the last month of life*, your relative received good care when you were not able to be with him/her?

How satisfied are you with home care services your relative received *in the last month of life*?

How satisfied are you that health care workers worked together as a team to look after your relative *in the last month of life*?

How satisfied are you that you were able to manage the financial costs associated with your relative's illness *in the last month of life*?

How satisfied are you with the environment or the surroundings in which your relative was cared for *in the last month of life*?

How satisfied are you that the care and treatment your relative received *in the last month of life* was consistent with his or her wishes?

Note: The "Illness Management" domain is one of six domains comprising the CANHELP Bereavement Questionnaire. Mean scale scores are calculated for each domain of the questionnaire. In addition, an "Overall" satisfaction score is calculated. Please note that there is another version of the survey—CANHELP Lite—available from the [CARENET Web site](#) .

Rationale

Initiatives to improve satisfaction with end-of-life (EOL) care remain hampered by a nascent understanding of what quality care means to patients and their families, and how it is best measured. Several experts and professional societies have attempted to define the specific components and related areas (domains) involved in quality EOL care; in contrast, patient and family perspectives are surprisingly lacking.

Most previous studies of quality have focused on outpatients and people with cancer. Researchers recently documented that most Canadians (greater than 70%) die in hospitals, and the majority of decedents are elderly patients who died from causes unrelated to cancer. The trajectory of a patient dying from cancer differs from one dying from other, chronic, end-stage medical conditions. Thus, issues deemed important to quality EOL care that were identified by previous investigators may not be generalizable to seriously ill patients with advanced disease other than cancer, who have a more uncertain prognosis.

Although a "quality death" is an espoused right of Canadians, for many dying patients and their families it is not achieved. Recent reviews and observational studies describe considerable dissatisfaction with EOL care, indicating that there are still opportunities for improvement. Ideally, initiatives aimed at improving EOL care would be informed by the experiences and expectations of patients and their family members. However, such efforts are often hampered by inadequate definitions of quality of care and by suboptimal tools for measurement.

In a recent review, few studies evaluated satisfaction with care at the EOL, and most used non-validated assessment tools. To advance this field, standardized, validated satisfaction questionnaires are needed to measure meaningful outcomes in order to evaluate the effects of various clinical, organizational, policy, and financial initiatives that influence how EOL care is delivered and experienced. By first understanding patients' and families' levels of satisfaction with key elements of EOL care, we will be in a better position to improve their individual care, and to introduce quality improvement initiatives to the health care system as needed.

The Canadian Health Care Evaluation Project (CANHELP) questionnaire was designed to evaluate satisfaction with care for older patients with life threatening illnesses, and their family members.

Evidence for Rationale

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Primary Health Components

End-of-life care; caregiver bereavement; illness management

Denominator Description

Number of questions answered by caregivers who completed the "Illness Management" domain on the Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire (see the related "Denominator Inclusions/Exclusions" field)

Numerator Description

Caregivers' ratings on the "Illness Management" domain on the Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire (see the related "Numerator Inclusions/Exclusions" field)

Evidence Supporting the Measure

Type of Evidence Supporting the Criterion of Quality for the Measure

Focus groups

One or more research studies published in a National Library of Medicine (NLM) indexed, peer-reviewed journal

Additional Information Supporting Need for the Measure

Unspecified

Extent of Measure Testing

Data were collected by a cross-sectional survey of patients who had advanced, life-limiting illnesses and their family caregivers, and who completed Canadian Health Care Evaluation Project (CANHELP), a global rating of satisfaction, and a quality of life questionnaire. Researchers conducted factor analysis, assessed internal consistency using Cronbach's alpha, and evaluated construct validity by describing the correlation amongst CANHELP, global rating of satisfaction and the quality of life questionnaire scores. There were 361 patient and 193 family questionnaires available for analysis. In the factor analysis, researchers identified six easily interpretable factors which explained 55.4% and 60.2% of the variance for the patient and caregiver questionnaire, respectively.

For the patient version, the subscales derived from these factors were Relationship with Doctors, Illness Management, Communication, Decision-Making, Role of the Family, and Your Well-being. For the family questionnaire, the factors were Relationship with Doctors, Characteristics of Doctors and Nurses, Illness Management, Communication and Decision-Making, Your Involvement, and Your Well-being. Each subscale for each questionnaire had acceptable to excellent internal consistency (Cronbach's alpha ranged from 0.69–0.94). Researchers observed good correlations between the CANHELP overall satisfaction score and global rating of satisfaction (correlation coefficient 0.49 and 0.63 for patient and family, respectively) which was greater than the correlations between CANHELP and the quality of life instruments. Researchers concluded that the CANHELP Questionnaire is a valid and internally consistent instrument to measure satisfaction with end-of-life care.

Evidence for Extent of Measure Testing

Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y, Jiang X, Day AG, Cohen SR, Canadian Researchers at the End of Life Network. The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) Questionnaire. *Palliat Med.* 2010 Oct;24(7):682-95. [PubMed](#)

State of Use of the Measure

State of Use

State of Ohio

Current routine use

Current Use

not defined yet

Application of the Measure in its Current Use

Measurement Setting

Assisted Living Facilities

Home Care

Hospices

Hospital Inpatient

Skilled Nursing Facilities/Nursing Homes

Professionals Involved in Delivery of Health Services

not defined yet

Least Aggregated Level of Services Delivery Addressed

Single Health Care Delivery or Public Health Organizations

Statement of Acceptable Minimum Sample Size

Unspecified

Target Population Age

Age greater than 55 years old

Target Population Gender

Either male or female

National Strategy for Quality Improvement in Health Care

National Quality Strategy Aim

Better Care

National Quality Strategy Priority

Person- and Family-centered Care

Institute of Medicine (IOM) National Health Care Quality Report Categories

IOM Care Need

End of Life Care

IOM Domain

Patient-centeredness

Data Collection for the Measure

Case Finding Period

Unspecified

Denominator Sampling Frame

Patients associated with provider

Denominator (Index) Event or Characteristic

Patient/Individual (Consumer) Characteristic

Denominator Time Window

not defined yet

Denominator Inclusions/Exclusions

Inclusions

Number of questions answered by caregivers who completed* the "Illness Management" domain on the Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire

*The domain scores are considered missing if more than half of the responses for that domain are missing.

Exclusions

Unspecified

Exclusions/Exceptions

not defined yet

Numerator Inclusions/Exclusions

Inclusions

Caregivers' ratings (1 = "Not at All Satisfied"; 2 = "Not Very Satisfied"; 3 = "Somewhat Satisfied"; 4 = "Very Satisfied"; 5 = "Completely Satisfied") on the "Illness Management" domain on the Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire

Note:

The "Illness Management" domain score is the average of non-missing questions specific to this domain. The "Overall" satisfaction score is the unweighted average of all answered questions.

All scores are re-scaled to range between 0 (worst possible value) and 100 (best possible value).

Exclusions

Unspecified

Numerator Search Strategy

Fixed time period or point in time

Data Source

Patient/Individual survey

Type of Health State

Does not apply to this measure

Instruments Used and/or Associated with the Measure

Canadian Health Care Evaluation Project (CANHELP) Bereavement Questionnaire

Computation of the Measure

Measure Specifies Disaggregation

Does not apply to this measure

Scoring

Composite/Scale

Mean/Median

Interpretation of Score

Desired value is a higher score

Allowance for Patient or Population Factors

not defined yet

Standard of Comparison

not defined yet

Identifying Information

Original Title

Illness management.

Measure Collection Name

Canadian Health Care Evaluation Project (CANHELP) Questionnaire

Measure Set Name

Bereavement Questionnaire

Submitter

Heyland, Daren K., MD, MSc - Independent Author(s)

Developer

Heyland, Daren K., MD, MSc - Independent Author(s)

Funding Source(s)

This study was supported by the Canadian Researchers at the End of Life Network (CARENET). CARENET is supported by a grant from the Canadian Institutes of Health Research and the Heart and Stroke Foundation of Canada.

Composition of the Group that Developed the Measure

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Financial Disclosures/Other Potential Conflicts of Interest

None declared.

Adaptation

This measure was not adapted from another source.

Date of Most Current Version in NQMC

2014 Nov

Measure Maintenance

Unspecified

Date of Next Anticipated Revision

Unspecified

Measure Status

This is the current release of the measure.

The measure developer reaffirmed the currency of this measure in January 2017.

Measure Availability

Source available from the [CARENET Web site](#) .

For more information, contact Dr. Daren K. Heyland at Kingston General Hospital, 76 Stuart St., Angada 3, Kingston, ON, K7L-2V7; E-mail: dkh2@queensu.ca; Web site: www.thecarenet.ca/resource-center/canhelp .

Companion Documents

The following are available:

Heyland DK, Cook DJ, Rocker GM, Dodek PM, Kutsogiannis DJ, Skrobik Y, Jiang X, Day AG, Cohen SR, Canadian Researchers at the End of Life Network. The development and validation of a novel questionnaire to measure patient and family satisfaction with end-of-life care: the Canadian Health Care Evaluation Project (CANHELP) Questionnaire. Palliat Med 2010 Oct;24(7):682-95.

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NQMC Status

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No copyright restrictions apply.

Production

Source(s)

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